The prospective Nationwide Study of Perthes` Disease in Norway: Functional and Radiographic Outcomes at a Mean Follow-up of Twenty Years

Date 01.11.2018

Perthes study group

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The society of children's orthopaedics initiated a nationwide study on Legg- Calve Perthes disease (LCPD) in 1996. All hospitals with orthopaedic service were involved and all new diagnosed patients with LCPD were registered. Several studies (1-7) were published based on this nationwide study. Ola Wiig and Stefan Huhnstock are members of the International Perthes Study Group, Texas Scottish Rite Hospital.

Background

LCPD is a juvenile hip disease which affects children between 2 and 12 years of age. It is most commonly seen boys at the age around 5-6 years. The aetiology is still unknown. The pathophysiological key event is a partial or complete disruption of the blood supply to the femoral epiphysis. The epiphyseal cartilage, the secondary ossification centre and the metaphysis undergo subsequent changes due to partial or complete osteonecrosis. In the active stages of the disease the femoral epiphysis may deform due to altered mechanical properties. At time of healing the femoral head shape may vary compared to a normal hip. Depended on the residual deformity the patients may have symptoms and complaints even after time of healing and the hip function may be impaired in young adulthood. Such a hip may also predispose for early hip osteoarthritis.
Since symptoms and hip changes are not only restricted to the active phases of the disease, it is mandatory to follow up the patients over a longer period. This study elucidates the hip function, the residual deformity and the patients reported outcome 20 years after the diagnosis with LCPD:

Unsolved issues with LCPD

LCPD has been described for more than 100 years ago(8-10). However, there is no clear consensus on the epidemiology, aetiology the prognostic factors and treatment.

The treatment has changed dramatically in Norway over the last decades. Until the late 70s, children had been treated with traction and weight relief over several months in the active stages. Later, containment treatment was introduced and several orthotic devices had been introduced in order to maintain hip containment. Surgical Containment gained increasing popularity from the late 80s until today.

There is no consensus which treatment gives the most favourable outcomes. Several studies have been published and the results concerning the surgical (7, 11-13) or non-surgical treatment is very divergent (14-16). Most of the studies are retrospective and have a short follow up time. Those studies therefore fail to evaluate the hip shape at time of healing. The main endpoints of most of the studies are based on radiographs, leaving the functional aspect unrecognized. Thus, little is known about patient’s hip function, quality of life and treatment satisfaction.

Purpose of the study

The purpose of the study is to evaluate long term outcomes, risk factors and patient reported outcomes in young adults, 20 years after LCPD.

Material and methods

From January 1996 until December 2000 al new diagnosed children with LCPD were registered in a nationwide Perthes study. It is a prospective, multicentre study involving 28 hospitals throughout Norway. The diagnosis was established by the local

orthopedic surgeon based on radiographic findings and clinical diagnostic. All radiographs were reviewed by Svein Svenningsen, Ola Wiig or Terje Terjesen. A total of 425 children with LCPD were involved in the study.

The study will follow up all 425 patients and it is structured in 3 phases.

Phase 1: Follow-up of all patients in the South-Eastern Norway Regional Health Authority (HSØ)
208 patients with LCPD have been registered in HSØ(163 males and 45 females). Average age at diagnosis was 5.8 years (1.3 – 15.2).

Phase 2: Follow-up of all patients in the Western and Central Norway Regional Health Authorities (HVoM)
187 patients with LCPD have been registered in these two regions (141 males and 46 females). Age at diagnosis was 5.7 years (1.7 – 13.5). 93 were treated with physiotherapy, 82 were treated with surgery and 11 patients with orthosis.

Phase 3: Follow-up of all patients in the North Norway Regional Health Authorities (HN)
27 patients with LCPD have been registered in this region (18 boys and 9 girls). Age at diagnosis was 6.1 years (1.8 – 13.1). 11 patients were treated with physiotherapy and 16 with orthosis.

Demographics and clinical information have been reported of all 425 patients at the initial visit. Radiographs at diagnosis, 1 year and 5 years follow-up were collected. The extent of the femoral head necrosis was evaluated with the Catterall and lateral pillar classification (17, 18). At 5 years follow-up the residual deformity was classified with the modified Stulberg's classification
The present study is planning to invite all 425 patients to a clinical and radiographic examination. The project starts in 2019 with a pilot study where 20 randomised patients will be examined.
The main study will proceed with the phases as described above. The examination will comprise a clinical visit with functional testing of the hip and radiographs of both hips.

Endpoints (primary /secondary)

Clinical endpoints will be the hip function and quality of life reported by the patients, using the Hip disability and Osteoarthritis Outcome Score (HOOS) (20). There will also be included functional and activity related aspects of a greater population based study in Oslo (21). Furthermore, length leg discrepancies, muscle impairment and Hip impingement tests will be performed.
HOOS: Validated PROM.40 questions to evaluate hip symptoms, hip function on different activity levels and quality of life.

«Oslo population study»: Scientific population study in Oslo to evaluate cardiac risks (21).

If patients would like to participate in the study, but fail to meet up for the visit, a short telephone interview will be performed including a short HOOS_PS form.

Radiological endpoints

a.) Stulberg classification
b.) Coverage of the femoral head (CE angle)
c.) Osteoarthritis - Jacobsen et al.(22)
d.) Alterations of the proximal femur (ATD, CCD)
e.) Total hip replacement.

Significance

The Norwegian Perthes study is unique in the world. It is the world largest prospective study on Perthes disease. Other long term studies on LCPD are retrospective and they do not investigate the hip function. A variety of different classifications have been used, which makes a direct comparison impossible.
No study has been using PROMS in the patient assessment. The present study will be the largest prospective study on this field. It elucidates both radiographic and clinical aspects 20 years after the diagnosis. The results may therefore have a significant impact on a better understanding and the future treatment of LCPD.

Plan

2018	Identification of all pasients
2018 - 2019	Pilotstudy with 20 randomised pasients
2019	Dataanalysis og pilot study
2019 - 2020	Phase 1
2020	Data analysis Phase 1
2020 – 2021	Phase 2:
2022	Data analaysis
2023	Phase 3:
2023	Data analysis
2023 – 2025	Publication

Relevant literature

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